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War on Two Fronts: Experience of Children with Cancer and Their Family During COVID-19 Pandemic in Iran

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ABSTRACT

Introduction: The COVID-19 pandemic affects all age groups and presents differently in children from adults. Children who contract the virus while suffering from cancer may face unique health challenges than their counterparts. This study aimed to investigate the perspectives of children with cancer and their family in this era of the COVID-19 pandemic.

Methods: In this qualitative study, a total of 21 participants were interviewed. They include five children, thirteen mothers, a father and three pediatric oncology nurses. The study setting was a Pediatric Hospital in Tehran, Iran.

Results: Three main themes were identified through thematic analysis. 1) Swinging on the path of fear to adaptation, 2) Left-alone at emotional distances, 3) Care system confusion, and decreased quality of care.

Conclusions: The COVID-19 pandemic has burdened children living with cancer and their families in varying ways. Their experiences show a new insight on how to improve their quality of life during these difficult times.

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Introduction

In December 2019, COVID-19 was discovered in China and had since spread rapidly to many countries worldwide (She & Liu, 2020). In Iran, early reports of the virus emerged from Qom province on February 19 2020. Several people have since contracted the disease, leaving many others dead (Abdi, 2020). COVID-19 is an acute pulmonary infection caused by a coronavirus. The disease manifests with various clinical presentations ranging from asymptomatic to respiratory failure that may require special care (Kotecha, 2020; Ruggiero, Romano, & Attinà, 2020).

According to the recent literature, the COVID-19 pandemic affects all age groups, but its presentation is different in children from adults (She & Liu, 2020). In a nationwide case series of 2143 pediatric patients with COVID-19 that reported to the Chinese Center for Disease Control and Prevention from January 16 to February 8 2020, there were 731 laboratory-approved samples and 1412 suspected COVID-19 cases in children aged 2 to 13 years. Out of these, 90 patients were asymptomatic or had mild to moderate symptoms (Dong et al., 2020).

Although COVID-19 is less common in children or may present with mild symptoms, adults with a weakened immune system due to chronic diseases such as cancer are at increased risk of suffering from the devastating effects of the virus (Saroha & Moulik, 2020). The first case of COVID-19 in children with cancer was identified on March 8, 2020, in

Wuhan (China) (Chen et al., 2020). A study published in April 2020 reported that nine children aged 2 to 10 years, were infected with COVID-19 in some pediatrics hospitals in Iran, including three children with leukemia and lymphoma (Rahimzadeh et al., 2020). A study conducted in Italy reported that adolescents and young adults with cancer aged 15–21 years are at higher risk of the COVID-19 infection compared to their healthy counterparts (Casanova et al., 2020).

Cancer is a complex and life-threatening disease that affects various aspects of life and exposes sufferers, especially children, and their families, to numerous health and psychosocial challenges (Jibb et al., 2018). Notably, due to the immune suppression effect of cancer and its related therapies, it increases the risk of different infectious diseases, including COVID-19 among patients (Loeffen et al., 2019). Therefore, children who are in contact with COVID-19 while having cancer may face unique health challenges that are different from their healthy counterparts (Kotecha, 2020).

This situation has made parents of children with cancer, overly worried about the possible consequences of cancer and the COVID-19 pandemic (Kotecha, 2020). Darlington's study conducted in the United Kingdom also showed that the COVID-19 had increased the psychological, social, and economic burden of parents of children with cancer. The parents believe that their children are at increased risk of infection compared to their healthy counterparts (Darlington et al., 2020).

It seems that struggling with both conditions (cancer and COVID-19), as two complex and deadly diseases, has created a new challenges for children and their families. This experience is entirely different from

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the experiences of healthy people who face COVID-19 and therefore require in-depth understanding. Discussing concerns and responses to COVID-19 with children with cancer and their families during this pandemic will shed light on the impact of COVID-19 on their lives. This understanding could lead to the development of more practical ways that would improve the quality of life of these children and their families. Therefore, the current study aimed to investigate the perceptions of children living with cancer and their families as well as oncology nurses in the era of the COVID-19 pandemic.

Methodology

Study design

The current study is part of a broader study among children with cancer who are receiving treatment at the Central Pediatrics Hospital in Tehran, Iran. During the data collection phase of the initial research, the COVID-19 pandemic had begun, thereby necessitating this investigation of the impact of the pandemic on children with cancer. To investigate how children living with cancer and their parents experienced the effect of COVID-19, we conducted this qualitative study using the thematic analysis approach in an open-ended way, consistent with Braun and Clarke (2006). Thematic analysis is a method for identifying, analyzing, and reporting patterns (themes) within data (Braun & Clarke, 2006).

Procedure

All participants received treatment in one hospital (Central Pediatrics Hospital) in Tehran Province. Participants included children living with cancer, parents, and pediatric oncology nurses. It must be noted that the main participants were children and parents; however, references from the data to the pediatric oncology nurses necessitated interviews with them as well. All the children who participated received cancer treatment either as inpatients or outpatients. The pediatric oncology nurses who participated in the study worked in the inpatient ward.

Due to the recent social distancing and lockdown regulations, the participants in this study were interviewed through phone calls. Telephone interviews are widely used in qualitative research to conduct in-depth interviews in situations where face-to-face conversations are not possible (Saroja & Moulik, 2020). Participants were selected using a purposive sampling technique. The sampling continued until sufficient knowledge about the research questions was obtained. Data collection stopped when data saturation was reached.

The participants were selected based on the researcher's previous knowledge of families with children living with cancer. The objectives of the study were explained to each participant, and they were well informed that interviews would be recorded. If they agreed, the meetings were then scheduled. Interviews were semi-structured, using interview guidance (Table 1). To develop the interview questions, two authors (JM and FE) individually made an initial outline of possible problems relevant to the purpose of this study. Then appropriate questions were selected through discussion between them. All questions were followed by in-depth probing. The study received ethical approval from the ethics committee of Tehran University of Medical Sciences.

Data analysis

The data were organized using the MAXQDA software version 10. Following Braun and Clarke (2006) approach of thematic analysis (Braun & Clarke, 2006), all interviews were recorded and given an identification code (Mother: M1, M2... / Father: F1, F2. / Nurse: N1, N2 / Child: C1, C2). The interviews were transcribed verbatim and read several times. This helped us to familiarize ourselves with the depth and breadth of the content and to search for meanings or possible patterns.

Table 1
Semi-structured interview questions.

Participants	Questions
Children	<ul style="list-style-type: none">– What changes have occurred in your life since the beginning of the COVID-19 pandemic?– What is your feeling about the situation?– What changes have you observed in the process of receiving care in the hospital during this pandemic?– Would you please tell me about any other aspects of your care that you wish would have been different in light of the COVID-19 pandemic?
Parents	<ul style="list-style-type: none">– Please explain the effects of COVID-19 on your daily activities and that of your child.– What changes have you noticed in your child's life since the beginning of the COVID-19 pandemic?– How did your child react to the situation?– What changes have taken place in the process of receiving hospital care since the beginning of the COVID-19 pandemic?– Would you please talk about any other aspects of the care provided for your child that you wish would have been different in light of the COVID-19 pandemic?
Nurses	<ul style="list-style-type: none">– What changes have occurred in the process of providing hospital care for children with cancer?– What challenges do the children and their families face?

When the data was read, an initial list of ideas about what is interesting about them was generated and coded. In this study, the quotes from the children, parents, and nurses were analyzed together. Then the different codes were sorted into potential themes and collecting all the relevant coded data extracts within the identified themes.

Furthermore, some themes were categorized into similar and cohesive groups called sub-themes. The themes were reviewed in terms of internal and external heterogeneity. If necessary, the themes were changed, and some new themes were identified. An attempt was made to give the themes a short and concise name in such a way as to instill in the reader's mind what that theme is about. We used an inductive approach for this phase. As the final stage of the analysis, we selected examples from quotes, finalized analysis of quotations from some selected quotes, literature search, and prepared the scientific report.

Trustworthiness

Guba and Lincoln's criteria were used to validate the findings (Lincoln & Guba, 1985). To ensure credibility, the researcher's previous acquaintance with the cancer department and its patients was useful in understanding and analyzing the data. The themes extracted from the interviews were checked with the participants as needed, and discrepancies were adjusted. For confirm ability, two members of the research team analyzed the data independently and reached a consensus. To ensure dependability, the researchers conducted semi-structured interviews using an interview guide to explore the topic of interest. Transferability was achieved by describing the research context thoroughly and providing detailed explanations of the research process.

Results

In total, 21 participants were interviewed in this study that includes five children, thirteen mothers, a father, and three pediatric oncology nurses. The children and parents were from different families except for a father with the 14-year-old female and a mother with the 13-year-old female (Table 2). The data analysis produced three main themes include *swinging on the path of fear to adaptation*, *Left-alone at emotional distances*, and *Care system confusion and decreased quality of care*. Eight subthemes emerged alongside the three themes (Table 2).

Table 2
Characteristics of participants.

Parents				Children			Nurses
Parent	Child's sex	Child's age	Child's cancer diagnosis	Child's sex	Child's age	Child's cancer diagnosis	Work experience in the pediatric oncology
Mother	Female	7	*ALL	****Female	14	Lymphoma	Nurse with 2 years
***Mother	Female	12	Ewing's sarcoma	***Female	13	Ewing's sarcoma	Nurse with 3 years
Mother	Female	8	ALL	Female	13	ALL	Nurse with 6 years
Mother	Male	5	**AML	Female	15	ALL	
Mother	Male	9	ALL				
Mother	Female	6	ALL				
Mother	Female	3	ALL				
Mother	Female	2	ALL				
Mother	Male	4	ALL				
Mother	Female	5	ALL				
Mother	Female	3	ALL				
Mother	Female	5	ALL				
Mother	Male	5	ALL				
****Father	Female	14	Lymphoma				

*ALL = Acute lymphoblastic leukemia, **AML = Acute Myeloid Leukemia, *** From Same Family, **** From Same Family.

Theme 1: swinging on the path of fear to adaptation

1) Exposed to an unknown and enormous threat.

We understood that children living with cancer feel an enormous health challenge as well as the uncertainties arising from COVID-19. These have made the children and their families feel threatened. A Part of people's fears is related to the significant mortality rates, high rate of transmissibility, and inadequate knowledge of the virus. In particular, these children's weaker immune system has increased the anxiety in both parents and well-wishers. Although there is a constant need to observe public health protocols, access to most items needed for personal protection is currently limited in many jurisdictions.

"I have gotten used to cancer, I mean I know about it. However, corona is strange and unknown to me. So I am afraid of it more, and I am worried about getting the coronavirus."(C1). *"I am afraid of the corona. I am afraid of getting infected because everyone who gets it will die."*(C2). *"The immune system of my child is weakened because of cancer. My child is at an increased risk of COVID-19."*(M3). *"At the beginning of the outbreak, we had trouble getting masks, gloves, and disinfectants because of the shortages and high costs. Because of the cancer treatment, my child needs these."*(M4).

2) Developing strategies to address corona phobia.

The data analysis revealed that after a while, children and their families had experienced changes in their approach towards coping with COVID-19. This situation has persisted since the beginning of the outbreak until the time of this study (five months post-pandemic commencement). With the pandemic's prolongation, they inevitably altered their attitude from panic and complete alertness to trying to regain control living with the virus. They also developed strategies to deal with the fear of the disease by adapting themselves to the new situation.

"I was constantly following the corona news to get more information."(M5). *"I was washing my hands constantly until my skin became dry. Whenever I touched anything, I washed my hands immediately because I was afraid of getting infected."*(C1). *"We were terrified and anxious, but when we all stayed at home, the chance of getting the infection was reduced, and our anxiety was minimized."*(M3). *"Even talking about corona is scary. I do not talk about it, and I do not listen to the news to make myself less worried."*(C2). *"We try to follow hygiene principles and teach our children how and when to use a mask or wash their hands."*(M4). *"In coordination with the doctor, we made the treatment program more compact and changed it to outpatient treatment."*(M3). *"It is stressful for me that children with cancer are at increased risk of Coronavirus infection. However, when praying to God, I feel calm."*(M3).

Theme 2: left-alone at emotional distances

Children with cancer and their families have many emotional needs to deal with, and being together is an essential issue. However, the COVID-19 pandemic led to restrictions on person-to-person interactions. This situation created distance between some children and their relations, leading to diminished excitement in life. They faced restrictions such as physical separation and limited opportunity to interact with significant others.

"It has been about two months since my father avoided close contact with me so that I do not get corona. We cannot communicate with our relatives. Corona has created a gap between our loved ones and us and reduced affections."(C2).

The authorities restricted interactions in hospitals and other public places such as prohibiting visitors from entering patient rooms, disallowing the children from going out of the ward, and banning the entrance of amusement groups/persons. One of the main concerns of children was that their fathers were not allowed to visit them. Besides, some participants felt being as prisoners in a cage.

"My daughter is very dependent on her father. She misses him so much. Children are very bored here."(M12). *"Fathers are not allowed to enter the ward, which makes children and their fathers upset."*(M5). *"Playroom is closed. Children are not allowed to go out, and they are not allowed to play with other children."*(M6). *"Children are not allowed to go to the Playroom. No one comes here to amuse them. Mothers and children are not allowed to go to other rooms or to talk in the corridors. The feeling of empathy and happiness of mothers and children is gone. I feel bored and lonely."*(C2). *"It is tough for us. Corona has driven us crazy. We have been hospitalized for twenty days. My daughter misses her father. She doesn't eat. We are imprisoned in this room like a cage. We do not even leave the room, unless when they want to inject the medicine in my daughter's spinal cord. No one is allowed to visit us."*(M8). *"Since nurses and doctors are using masks and shields, the children and their mothers are not able to identify them. Wearing mask along with social distancing in the unit has led to severe communication problems and intensifies the feeling of loneliness and emotional distancing among the children and their families."*(M10).

Restricting interactions with the broader society is also common. Children are not allowed to attend school, nor have outdoor activities and no face-to-face contact with friends. These are mostly great sources of entertainment for many of these children. Therefore, feelings such as restlessness, loneliness and boredom were quite common among children.

"One of the favorite activities that brought me beautiful joy was attending school. When schools were closed, I lost my friends." (C4). "We had a plan to travel, but it was cancelled because of the corona. My daughter was attending music classes, and she was in contact with her friends. However, because of corona and the quarantine, everything ceased, and she feels bored and lonely. I feel her anger." (F1).

So far, children and families have already been battling cancer. The growing fear of COVID-19 has doubled their problems. Cancer and chemotherapy have already exposed them to various constraints. Now the fear of contamination by COVID-19 and concerns about their weakened immune system against COVID-19 has made their life-limitations far higher than other people.

"We had a lot of misfortune, the corona was added! Before corona, at least I used to take my son to the park once a month, but now I can no longer do that. Staying at home and being alone has made him more restless and troubled." (M7).

Theme 3: Care System Confusion and Decreased Quality of Care.

1) Sacrificing children and family's needs due to concentration on COVID-19 prevention.

COVID-19 Prevention becomes the main concern of the health care system. Therefore, children and family's needs no longer viewed as a priority in the care system. According to the findings, the COVID-19 pandemic over shadowed all families' needs and severely affected the quality and scope of care. Although children and their families were aware of the importance of special conditions related to the COVID-19 pandemic, the rules and restrictions imposed on them and the lack of attention to their needs created extra stress and worries.

"To be allowed to enter the ward, the mother and child must take a Corona test, which is expensive." (M5). "We did not allow fathers to visit their children, who caused many objections, from families and the children themselves." (N1). "Initially, I was not allowed to enter the ward. They said my daughter is old enough and does not need a companion. I spoke with the supervisor, and she said that if you had a corona test, you could enter the ward, and she informed the head nurse." (F1). "As before, there was no disinfectant in all rooms and inside the ward. If necessary, we should have asked the nurses to deliver us some disinfectant." (M2).

2) Confusion about issuing and implementing instructions.

Based on the narratives, the sense of security in the community and the hospital was limited, particularly as they were faced with one-sided hospital laws. They pointed out the problems of the system, such as community guidelines not fully implemented and compatible with those in the pediatric ward. Some of the instructions were theoretical, and it was not possible to implement them in practice due to shortages and lack of access to resources. Some hospitals imposed restrictions on the children and their families, which were difficult to comply with. These issues were particularly crucial for those hospitalized in the cancer wards.

"Some people do not respect public health instructions in the community or the hospital. Some people do not fully follow the principles of personal hygiene and health advice. Some doctors were using full personal protective equipment at the hospital, but some others only wore masks." (M1). "Many people emphasized that mothers and children should be tested for corona before hospitalization, but these rules were only for us children. Nurses and doctors or other non-cancer patients were not required to observe these rules." (M2). "Mothers and children were not allowed to enter the cancer ward with their shoes and were required to use special slippers provided by the hospital. This is for our

children's health, but why do they not observe this rule themselves and enter the wards with high heels? They are making it hard on us so that we do not carry corona to the ward. We do not even have the right to choose the right slippers for ourselves and our children, and we have to wear whatever they give us." (M2).

3) Children and Family Expectations from Medical Staff and Health System in the Context of the COVID-19 Pandemic.

Children with cancer and their families mentioned their expectations from the medical staff and the health system in their interviews. They expected to have access to personal hygiene equipment for their protection and others during hospitalization and to receive financial support to pay for the COVID-19 PCR Test. Besides, they noted that not only the patients and families need to follow the regulations related to personal hygiene, but also, medical staff should respect those rules. The children and their families explained that as much as they could spread the virus in the ward, the health personnel may also contribute to transmitting the virus. However, most of the restrictions were mainly for children and their families. One of the significant demands of children and their families from the medical staff during the COVID-19 pandemic is to pay attention to their need for continued communication and emotional support. Since the system is focused on controlling the spread of the virus, less attention is paid to emotional needs. Based on the participants' experience, children and their families did not receive any psychological or emotional support.

"These disinfectants are vital during the COVID-19 pandemic. When the pandemic is over, they no longer have value for us. We need these substances, and they should provide sufficient disinfectant for us. We are faced with different stresses. We do not want the medical staff to upset us and make the situation worse by creating such tensions." (M2). "The Corona test is expensive, and we cannot afford it. The head nurse or head of the cancer department should consider this issue and negotiate with the hospital to make this test free." (F1). "Nurses are more nervous than before and stay away from us. They do not spend enough time to answer our questions, and they just lead us to our rooms and tell us not to leave the room." (M2). "Some children want to play with me or talk to me or even hug me, but I have to avoid them. Because I have less time, and I have to observe COVID-19 related protocols." (N1).

Discussion

Our findings reflect the experiences of children with cancer and their families during the COVID-19 pandemic. In this study, the children expressed their concerns about being exposed to an unknown and enormous threat. In other words, children with cancer and their families emphasized that the pandemic overburdens them as they continue to live a life of uncertainty. They pointed out other significant concerns, such as changes in the process of treatment, the lack of effective treatment, and how the disease has become so widespread. It seems that these concerns have gone beyond the current locality to become a global concern, creating fear and anxiety among people from all walks of life (Lin, Hu, Alias, & Wong, 2020; Park et al., 2020; Zandifar & Badrfam, 2020).

People with underlying conditions may experience varying degrees of risk. For example, a recent study in Turkey found that children and adolescents with cystic fibrosis (CF) and their mothers experienced high levels of anxiety during the COVID-19 pandemic. The mothers, however, had higher stress levels than the children. Interestingly, in their study, children with CF had no elevated anxiety scores compared with the healthy children in the control group. The authors of the study explain that perhaps children with CF who have encountered the fear of disease before have developed more adaptive strategies to manage future crises compared with healthy children. This is a controversial issue that needs

more investigation. However, there was no significant relationship in comparing the severity of the children's anxiety, which is relates to their health state in terms of not getting COVID-19 because they have cystic fibrosis (Senkalfa & Eyuboglu, 2020).

In the current study, the participants mentioned cancer as a factor that increases the risk of the COVID-19 infection. Darlington found that mothers of children with cancer felt a higher risk for the COVID-19 disease. They were concerned about the weak immune system of children with cancer, the high-risk environment of the hospital, infection of family members, and the possibility of spreading the virus at home by parents (Darlington et al., 2020).

The findings showed that limited access to personal protective equipment affects children's emotions. They were overly worried about exposure and risk of contracting COVID-19. The shortage of personal protective equipment is a significant challenge for different countries, including Iran (Abdi, 2020). Not having access to personal protective equipment can increase the chances of direct contact with patients and medical staff with the virus (Gondi et al., 2020). This situation created a constant worry and could pose a threat to both the physical and mental health of children with cancer and their families.

After facing the COVID-19 crisis, children and families tried to develop strategies to address the fear of the COVID-19 pandemic. Since the pandemic persists, it has made children living with cancer, and their families find creative ways to adapt to the situation. In other words, they seem to be moving from a state of fear to finding ways to adjust to the new conditions created by the COVID-19 pandemic. So their responses range from panic to readiness to gain control over circumstances and learn to live with it. Evidence from a study conducted in the United States suggests that the most common approach to cope with COVID-19 stress and quarantine conditions were thought distraction, active adaptation, and seeking social and emotional support (Park et al., 2020).

In the current study, behaviors such as being alert and obsessive about personal hygiene could be linked to anxiety. In contrast, more adaptive practices such as staying at home, observing personal hygiene, using protective measures, and staying away from the news are in line with mental health advice and the COVID-19 prevention protocols (WHO, 2020). For example, the World Health Organization (WHO) recommends the following interventions to improve mental health during the COVID-19 pandemic: avoid hearing, reading, and frequent viewing of COVID-19 related news, which causes anxiety and depression. Also, WHO recommends obtaining information regarding essential measures to protect individuals against COVID-19 from sound sources such as ministries of health (WHO, 2020). Moreover, protocols on managing cancer during the COVID-19 pandemic include observing personal hygiene and reducing unnecessary visits to the hospital (Rahimzadeh et al., 2020). Some of these are in line with the adaptive approach used by our participants in the current study (Ruggiero et al., 2020). Since there are several ways to improve mental health during this pandemic, people may choose different approaches to cope with stress (Park et al., 2020), based on what works best. A fraction of the participants in this study seems to rely on spirituality to strengthen their ability to cope with the unprecedented and threatening situation.

The participants in this study expressed feelings similar to being left alone at an emotional distance. During the pandemic, children and families are forced to follow isolation principles that limit their life activities such as attending school and meeting with friends and acquaintances. These rules intensified the feelings of loneliness and isolation (Jibb et al., 2018). The coexistence of the COVID-19 pandemic with cancer complicates the situation for the children and their families. Dealing with life-threatening illnesses such as cancer at the time of a pandemic is difficult and challenging for the children and their families. Coping with this situation requires emotional and social support (Pedro, Galvão, Rocha, & Nascimento, 2008). The COVID-19 pandemic, the quarantine, and the necessity to observe physical and social distance at homes, hospitals, and communities led to the loss of emotional and social support provided by friends, family, relatives, medical staff, and

active cancer support groups. Furthermore, this adds to the intensity of the loneliness of children with cancer and families.

Regarding the care system confusion and decreased quality of care, the participants point out that, with the onset of the COVID-19 pandemic, the provision of healthcare services in hospitals changed significantly. Various protocols were introduced to control the infection, including wearing personal protective equipment, taking care of suspected and infected patients, hand washing and disinfection of surfaces in clinical settings (ECDC, 2020). For the prevention and management of COVID-19 in the pediatric cancer wards, it is recommended to limit medical staff, restrict visitors and the number of visits to each patient, use appropriate personal protective equipment for medical and non-medical staff working in the ward and suspending all optional activities (Ruggiero et al., 2020). Due to these new recommendations, children and families felt their needs were not a priority to the health care system and workers anymore, since their focus was on infection prevention and mandatory restrictions. Patients and their family were concerned about the decreased quality of care in the hospital.

Table 3

Themes and subthemes reflecting the experiences of children with cancer and family during COVID-19 pandemic.

Theme	Subtheme	Sub/Subtheme
Swinging on the path of fear to adaptation	Exposed to an unknown and enormous threat	Faced with an unknown deadly disease with no hope for definitive treatment. Overburdened mortality rates The COVID-19 infection susceptibility in children with cancer Limited access to protective equipment Being alert Obsessive attention to personal hygiene Staying at home as a safe place to avoid corona infection Avoiding news about the COVID-19 pandemic Get trained and paying more attention to personal hygiene. Adjusting the treatment plans Strengthening spirituality
	Developing strategies to address corona phobia	Restricting interactions with family members at home Restricting interactions in the hospitals and public places Restricting interactions in society Disrupting the natural rhythm of life Feeling restless and bored High costs of corona tests Separating parents and children due to restrictions on visitations Shortage of equipment and limited access to personal hygiene items
Left-alone at Emotional Distances	Prisoners in a cage	
	Accumulated hardships	
Care system confusion and decreased quality of care	Sacrificing children and family's needs due to concentration on the COVID-19 prevention	
	Confusion about issuing and implementing instructions Children and family expectations from medical staff and health system in the context of the COVID-19 pandemic	

Table 4

Some recommendations to healthcare systems and staff to improve the quality of life in children with cancer during the COVID-19 pandemic.

Purpose	Recommendations
Fear control and effective adaptation improvement	<ul style="list-style-type: none"> • Providing mental health counseling support to children and their families to increase their adaptability to the new situation. • Providing educational support to children and families to cope with COVID-19 by taking into account the circumstances of patients with cancer.
Reducing the feeling of loneliness	<ul style="list-style-type: none"> • Providing the possibility of telephone and virtual medical consultations for children. • Considering happy virtual entertainment programs for children during their hospital stay. • Encouraging children and families to maintain their communications with other family members through telephone or video calls. • Using creative methods to interact with the children and family, such as posting motivational messages on notice boards to increase children's hope. • Maintaining and strengthening appropriate verbal and non-verbal communications with children and family while maintaining physical distancing. • Helping children to express feelings, fears, and worries by encouraging them to talk or draw or write stories
Improving the quality of care	<ul style="list-style-type: none"> • Providing an opportunity for children and families to participate in intradepartmental decision-making meetings and to express their needs. • Providing financial support to the families as well as free diagnostic tests for COVID-19. • Preparing children and families to face the new healthcare regulations in the cancer ward by providing clear explanations and creating an opportunity to ask questions. • Providing personal protective equipment for children and families.

Participants mentioned that in some cases, intra-sectoral rules and regulations led to conflicts between parents and health care workers. For example, imposing the pharyngeal PCR test for COVID-19 on patients and their relatives was one of the issues that were raised by parents. This move created a significant burden on families since many are already struggling to keep up with expensive cancer treatments. In other instances, the participants talked about the considerable time that nurses and physicians had to spend on the existing restrictions such as personal hygiene and personal protection. As a result of these new circumstances, the medical staff had little time to attend to usual needs of children and their families. At the same time, children had to adjust and fight two serious illnesses simultaneously.

Some experiences the participants shared were about the inconsistencies of the health system in issuing appropriate instructions and monitoring the implementation of the new rules and regulations in the community and medical settings. Most children with cancer rely heavily on regular medical services to maintain a good life. The pandemic has, therefore, created disruptions in accessing these services. Mainly, the unmatched instructions at various service points have worsened the situation, with every unit to a service center having unique protocols. Health care systems could use the support of international regulators in designing and implementing effective interventions (Raofi et al., 2020).

The data analysis revealed those children with cancer and their families have expectations from the medical staff's commitment and health system in the context of the COVID-19 pandemic. These expectations include providing the necessary public health items, financial support for

COVID-19 diagnostic tests, and the commitment of medical staff to comply with the issued rules regarding prevention of spreading the disease, paying attention to communication improvement, and meeting the emotional needs of children. In other words, children with cancer and their families, as vulnerable groups to the COVID-19 pandemic, need more financial and psychological support. Consistent with the findings of the current study, Darlington reported that in Britain, mothers of children with cancer expect economic and social assistance because of the effects of the COVID-19 pandemic on their living conditions (Darlington et al., 2020).

Limitations

The inability to conduct face-to-face interviews due to the pandemic made it impossible for observational and field notes to be taken, which we believe could be a limitation. However, based on researchers' experience, this restriction did not affect the depth and quality of the interviews, and the interviewers did their best to obtain in-depth information through telephone interviews. Also, the study population is not enough to draw a generalized conclusion that represents the larger group, especially the few nurse participants. Besides, participants were only recruited from a single center using a convenience sampling method. This could deny the study some relevant information. The findings of this study, therefore, should be interpreted with caution.

Practice implications

While practical adjustments are required in the healthcare system to minimize the economic burden on patients and their families, healthcare workers must communicate effectively and empathically. These are highly desired in improving patient outcomes and quality of life during these difficult times. The information was discovered in this study is not only relevant to pediatric oncology nursing practice, but also appropriate to oncologists, psychologists and social workers for giving them a clear view of the practice in the COVID-19 pandemic for children living with cancer and their families.

Conclusions

The COVID-19 pandemic has several effects on the lives of children living with cancer and their families. Reviewing their experiences show a new perspective on how to improve their quality of life during these difficult times. Managing cancer alone is challenging and complex for children and their families. With the advent of the COVID-19 pandemic, they require more support and attention from medical staff and the health system to go through this period with minimum physical and psychological damage. We have, therefore, tabled some recommendations to healthcare systems and teams (Table 3). (See Table 4.)

CRediT authorship contribution statement

Jila Mirlashari: Methodology, Data curation, Formal analysis, Writing - review & editing. **Fatemeh Ebrahimpour:** Conceptualization, Methodology, Software, Investigation, Data curation, Formal analysis, Writing - review & editing. **Waliu Jawula Salisu:** Data curation, Formal analysis, Writing - review & editing.

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